

Solve-RD Publication Policy

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| Version | 2 |
| Date | Final V2 18 April 2018 |
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| Approved by SC | 24.4.2018 |

1 Solve-RD as an author (if allowed for by journal)

An affiliation list will be created and regularly updated and will contain all members of the Solve-RD consortium (see Annex I). This list will determine the Solve-RD author ('Solve-RD consortium'). The author list will be reviewed and updated with each publication submission that makes use of the author list by the project management team (lead: Holm Graessner). The Solve-RD author shall be used for all publications if allowed for by the journal.

2 Notification and authorship policy with regard to shared data

All Solve-RD publications are acknowledged to be based on the fundamental principles of open scientific collaboration, reciprocity, attribution and benefit sharing. For any publication resulting from work carried out using data shared or generated through Solve-RD (e.g. for identifying a novel gene), including where data has been accessed through the RD-Connect Genome-Phenome Analysis Platform, the authors should in all cases acknowledge and give appropriate authorship positions to all relevant parties in line with best practice for acknowledgement of scientific contribution including submission of the primary data.

Examples and further principles are described below.

- 1. A publication arising from research in which the party leading the publication ("the PI team") is primarily analysing their own submitted data (example: novel gene discovery by a submitter analysing their own patient cohorts in the RD-Connect GPAP):**
 - i. Where a publication only includes data and hypotheses from the PI's own research group, key authorship positions may be held by this group, but the software, tools and resources made use of for the research should be duly acknowledged and referenced in line with the policies for those resources (e.g. see RD-Connect GPAP policy below). Where justified, individuals supporting the bioinformatics analysis or platforms may be approached for co-authorship based on individual scientific contribution.
 - ii. Where a publication has involved the use or analysis of data from additional submitters, these submitters should be contacted as soon as possible ahead of publication and invited to provide input as co-authors. The PI team is strongly encouraged to share key authorship positions with other teams that have brought in similar intellectual input and/or fundamental data (e.g. "a second family"). Acknowledgement of bioinformatics support should also be considered as in (a) above.
- 2. A publication arising from the analysis of data where the party generating the hypothesis and carrying out the analysis is not themselves the data submitter (example: reanalysis of data by a Solve-RD bioinformatics group that did not submit the data or see the patients):**
 - i. Submitters of the data used for the analysis should be contacted as soon as possible ahead of publication and invited to provide input as co-authors. The PI team is strongly encouraged to share key authorship positions with the submitting teams based on the value and amount of data contributed to the publication. If the primary data is the key to discovery, a key authorship position should be discussed with the owner of the primary data.

- ii. Where a publication makes use of data from a large number of submitters or transversal analysis of the Solve-RD cohort, a group authorship for Solve-RD should be considered in order to acknowledge the role of all data submitters equally.

All data access through the RD-Connect genome-phenome analysis platform is monitored automatically by the system and all other data access for other Solve-RD activities is only to named individuals within the Solve-RD consortium, therefore any breach of the publication policy will be monitored and flagged up to the Solve-RD Steering Committee.

3 Confirmation of paper by Solve-RD Consortium

During the project and for a period of one (1) year after the project every paper that is published with affiliation of Solve-RD or includes data produced or collated within Solve-RD has to be confirmed by the Solve-RD Consortium. The procedure is defined in Article 29.1 of the Solve-RD Grant Agreement and Article 8.4.2 of the Solve-RD Consortium Agreement. All Parties and associated Partners (including associated ERNs) are obliged to follow this procedure.

Prior notice of any planned publication shall be given to the other Parties at least 45 calendar days before the intended date of publication. Any objection to the planned publication following the above notification shall be made in accordance with the Grant Agreement in writing to the Coordinator and to the Party or Parties proposing the dissemination within thirty (30) calendar days after receipt of the notice. If no objection is made within the time limit stated above, the publication is permitted.

An objection is justified if (a) the protection of the objecting Party's Results or Background would be adversely affected and/or (b) the objecting Party's legitimate academic or commercial interests in relation to the Results or Background would be significantly harmed.

The objection has to include a precise and reasonable request for necessary modifications, it being specified that any such modifications shall not harm the scientific content of the proposed publication or communication.

If an objection has been raised the involved Parties shall discuss how to overcome the justified grounds for the objection on a timely basis (for example by amendment to the planned publication and/or by protecting information before publication) and the objecting Party shall not unreasonably continue the opposition if appropriate measures are taken following the discussion. The objecting Party can request a publication delay of not more than 90 calendar days from date of submission to the other Parties. After 90 calendar days the publication is permitted provided that Confidential Information of the objecting Party has been removed from the Publication and all reasonable modifications of the objecting Party have been implemented within the Publication as indicated by the objecting Party.

A decision has to be made and communicated within four weeks after submission of the publication draft (author list and abstract) to the Steering Committee.

4 Parallel Analysis of submitted data at centres

The Steering Committee has to be informed if data sets that were submitted to Solve-RD for central analysis go through in house analysis that may lead to publications.

5 Acknowledgements

Solve-RD funding acknowledgement

Any publications arising from Solve-RD project funding should acknowledge it in the following way:

“This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 779257 (Solve-RD).”

RD-Connect GPAP acknowledgement

In addition to authorship positions as described above, any publications that arise from the use of the RD-Connect Genome Phenome Analysis Platform should acknowledge it in the following way:

“This study makes use of data shared/provided through RD-Connect, which received funding from the European Union Seventh Framework Programme (FP7/2007-2013) under grant agreement No. 305444.”

In addition, the following paper should be cited:

Lochmüller H & Badowska D, Thompson R, Knoers N, Aartsma-Rus A, Gut I, Wood L, Harmuth T, Durudas A, Graessner H, Schaefer F & Rieß O. RD-Connect, NeurOmics and EURENomics: Collaborative European Initiative for Rare Diseases. European Journal of Human Genetics. 2018.

ERN acknowledgement

Any publications with contributions from ERNs should acknowledge involved ERNs in the following way:

“This study was supported by the European Reference Network(s) [add ERN names] (https://ec.europa.eu/health/ern/networks_en).”

Annex I: Solve-RD author list